Lessons From My Teachers

Category: Stories
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In July 2003, a few days after I had started service as inpatient attending pediatric cardiologist at Lutheran General Children’s Hospital, the neonatologists, nurses and I met with Jenni and Tony to discuss their daughter Grace’s health status.

Grace, now two and a half weeks old, had seemed normal at birth. After a few hours, her skin color had turned blue: Her oxygen level was dangerously low. She’d been whisked off to the neonatal intensive-care unit (NICU), where tests showed that her heart function was poor due to high blood pressure in her lungs. Her heart and lungs began to fail, so we’d placed her on a heart-lung machine (ECMO) for sixteen days. Now taken off the machine, she was breathing with the help of a ventilator. I was relieved to see that her heart function had finally improved.

Despite her progress, though, Grace was still quite sick, and her prognosis was uncertain. I knew that my colleagues shared my apprehensions.

As we gathered around a large conference-room table, the room was quiet, except for the faint buzzing of an overhead florescent light.

Grace’s parents seemed nervous, but quietly confident. Jenni pushed back her blond locks, smiled and looked expectantly at us. Tony seemed almost joyful.

“It’s amazing how far Grace has come,” he said. “We’re excited she’s off ECMO! She’s so strong, even with everything she’s been through. She’s going to make it. Grace is a fighter, just like her mom!”

He tenderly stroked Jenni’s hand under the table.

“Tony’s right,” she said, nodding. “I felt her tiny hand squeezing my finger, and I can’t believe how strong her grip is. Grace is going to get through this.”

She and Tony were both schoolteachers; I could easily imagine their students eagerly soaking up their compassionate energy.

As both parents beamed, I felt I could almost read their minds: They knew their daughter would be okay.

Now it was time for the medical team to weigh in.

“Grace has come a long way,” said the neonatology fellow in her serious, staccato voice. “But she’s still really sick, so it’s important to remember that she might not survive.”

“We’ve taken care of lots of children like Grace,” her nurse added. “You need to expect a long road ahead, with no guarantees that she’s going to be able to go home.”

The attending neonatologist spoke next: “We’re doing everything we can,” he said, “but unfortunately, many kids as sick as Grace don’t make it.”

While the team talked, I looked at Jenni and Tony. With each comment, their smiles faded a bit.

Tony’s ruddy cheeks turned pale, and he began to scowl. Jenni’s eyes grew teary, and her shoulders slumped. She stared toward the far corner of the room, avoiding everyone’s gaze.

Except for the buzzing of the light overhead, the room was quiet. Everyone in the room was looking at me—presumably for more words of caution.

Seeing Grace’s parents’ despair, I felt fury welling up deep inside—fury at my colleagues. Was their negativity completely called for? It seemed to me that in trying to keep Grace’s parents from harboring unrealistic expectations, they’d overemphasized the risk that she might not survive.

My heart started to pound. My mouth was dry. I remembered something my mentor, Dr. Welton Gersony, taught me in fellowship:

“Once you tell a family their child might die, you never have to bring that up again. No parent will forget that. Some medical people are so concerned about ‘telling the truth,’ they destroy hope. Don’t do that, unless there really is no hope.”

But how to balance these two truths? With parents whose child was facing a life-threatening illness, what words could I use to acknowledge the truth while also keeping the right amount of hope alive?

Suddenly a powerful calm came over me—something that felt to me like what

Christians call “the peace that passes all understanding.” I knew what I had to say.

“Grace is sick,” I said gently. “I’ve taken care of similar kids who have died, so that still might happen.”

Tony and Jenni stared up at the ceiling, looking like they wanted to get this discussion over with.

“However,” I continued, “I think it’s important to remember that there is a chance Grace might live. I’ve taken care of kids like Grace, some even sicker, who survived. Grace might get through this and make it out of the NICU.”

I looked at Jenni and Tony. Their eyes met mine. Jenni’s eyes were red. Tony’s lips were quivering, but the color had returned to his cheeks.

He looked directly at me. “What’s your honest opinion? Is Grace going to make it?”

“I don’t know what’s going to happen,” I said. “I do know I’m going to do everything I can to help Grace have a good outcome. Each of us has a role to play: the nurses, the respiratory therapists, the doctors, the social workers, the chaplains—and especially her mom and dad.”

“But how?” Jenni asked. “What can we do?”

“What you’re already doing,” I said. “Show up, love her, touch her, sing to her, tell her you love her. Kids who are loved do so much better than kids who are ignored. If I were in her position, I would want to be loved by my mommy and daddy. Keep loving her.”

Tony smiled.

“We can do that,” he said. Jenni nodded and squeezed his hand.

After the meeting, I stopped by Grace’s bedside. She was hooked up to multiple EKG leads, a temperature monitor, a ventilator and a pulse oximeter. From time to time, she stretched her little arms and legs. The only sounds were the steady *beep, beep, beep* of the pulse oximeter and the intermittent *whoosh* of the ventilator. Tony and Jenni sat close beside her bed, looking exhausted but in love with their baby.

I pulled up a chair next to them.

“How are you doing after our meeting?” I asked.

“What you said was so important,” Tony answered. “You gave us hope.”

“Now we don’t feel so alone,” Jenni added. “Thank you.”

After that, it felt to me like we’d become a team, guiding Grace’s care. The three of us had come through the stressful conference knowing more clearly than ever that we’d all work together to help Grace have the best possible outcome.

After three months in the NICU, Grace was weaned off the ventilator. At four months of age, she was able to go home with oxygen, and by eighteen months she was weaned off oxygen.

Caring for critically ill children, as I do, I must often try to strike the right balance between optimism and realism—for myself, my colleagues, my patients and their families. Grace and her parents taught me something important in this regard; something along the lines of the serenity prayer. I try to accept the things I cannot change (sometimes people are quite sick) but try to find the courage to change the things I can (doing my best, and trying not to fight families in the hope arena).

Thanks to Grace and her parents, I’m a better doctor, a better advocate and a “realistic cheerleader” for my patients and their families during challenging situations.

On a sunny spring day, eighteen years after we’d first met, an envelope from Jenni and Tony arrived in the mail. Inside was an invitation to Grace’s high-school graduation. Reading it through moist eyes, I recalled our long-ago conference.

Jenni and Tony were right, I thought. *They were young, with no medical training—but they were right all along.*

Grace was going to make it.